



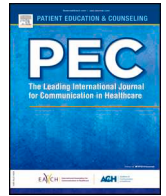
Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.



Contents lists available at ScienceDirect

## Patient Education and Counseling

journal homepage: [www.elsevier.com/locate/pec](http://www.elsevier.com/locate/pec)

# The impact of COVID-19 on cancer patients, their carers and oncology health professionals: A qualitative study

P. Butow<sup>a,\*</sup>, PE Havard<sup>a</sup>, Z. Butt<sup>a</sup>, Juraskova I<sup>a</sup>, L. Sharpe<sup>a</sup>, H. Dhillon<sup>a</sup>, L. Beatty<sup>b</sup>, P. Beale<sup>c</sup>, M. Cigolini<sup>d</sup>, B. Kelly<sup>e</sup>, RJ Chan<sup>f</sup>, L. Kirsten<sup>g</sup>, M. Best<sup>h</sup>, J. Shaw<sup>a</sup>

<sup>a</sup> Psycho-Oncology Co-operative Research Group (PoCoG), School of Psychology, University of Sydney, NSW 2006 Australia

<sup>b</sup> Flinders University, Órama Institute, College of Education, Psychology & Social Work, Adelaide, Australia

<sup>c</sup> Concord Clinical School, Faculty of Medicine and Health, University of Sydney, NSW 2006 Australia

<sup>d</sup> Department of Palliative Medicine, Royal Prince Alfred Hospital, Missenden Road, Camperdown, NSW 2050, Australia

<sup>e</sup> School of Medicine and Public Health, University of Newcastle, Callaghan NSW 2308, Australia

<sup>f</sup> Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Bedford Park, SA 5042, Australia

<sup>g</sup> Nepean Cancer Care Centre, Penrith, NSW 2751, Australia

<sup>h</sup> Institute for Ethics and Society, University of Notre Dame, Broadway, NSW 2007, Australia

## ARTICLE INFO

### Article history:

Received 6 September 2021

Received in revised form 27 January 2022

Accepted 28 January 2022

### Keywords:

Cancer  
Oncology  
Psycho-oncology  
Cancer patients  
Family members of cancer, patients  
Oncology health professionals  
COVID-19  
COVID  
Pandemic  
Coronavirus  
Fear and death anxiety  
Uncertainty  
Isolation  
Moral distress  
Work, stress

## ABSTRACT

**Objective:** Cancer patients, carers and oncology health professionals have been impacted by the COVID-19 pandemic in many ways, but their experiences and psychosocial responses to the pandemic are still being explored. This study aimed to document the experience of Australians living with cancer, family carers, and Oncology health professionals (HPs) when COVID-19 first emerged.

**Methods:** In this qualitative study, participants (cancer patients currently receiving treatment, family carers and HPs) completed a semi-structured interview exploring their experiences of COVID-19 and the impact it had on cancer care. Participants also completed the Hospital Anxiety and Depression Scale (patients) and the Depression, Anxiety and Stress Scale (carers and HPs) to assess emotional morbidity. Thematic analysis was undertaken on qualitative data.

**Results:** 32 patients, 16 carers and 29 HPs participated. Qualitative analysis yielded three shared themes: fear and death anxiety, isolation, and uncertainty. For HPs, uncertainty incorporated the potential for moral distress and work-stress. Patients and carers scoring high on anxiety/depression measures were more likely to have advanced disease, expressed greater death anxiety, talked about taking more extreme precautionary measures, and felt more impacted by isolation.

**Conclusion:** Cancer and COVID-19 can have compounding psychological impacts on all those receiving or giving care.

**Practice Implications:** Screening for distress in patients, and burnout in HPs, is recommended. Increased compassionate access and provision of creative alternatives to face-to-face support are warranted.

© 2022 Elsevier B.V. All rights reserved.

## 1. Introduction

COVID-19 has had an enormous impact on human mortality, morbidity and economic security worldwide, since it emerged. By March 2020, governments around the world had acted to contain the spread and impact of COVID-19, including imposing social distancing, mask-wearing and stay-at-home orders. While undoubtedly life-saving, these measures had their own consequences on mental

and physical health, particularly for those experiencing other stresses, such as being treated for a serious illness [1–3].

Cancer is a disease whose severity means that often treatment cannot be deferred or delivered remotely. Thus, patients must attend hospitals for at least part of their care, where they are at greater risk of exposure to COVID-19. Furthermore, some cancer treatments can cause immuno-suppression, leaving patients more at risk of COVID-19 infection and severe disease if they are exposed [4]. Infection-control rules were rapidly imposed by cancer services. Family members were excluded or severely limited from attending patient appointments and visiting hospitalised patients, impacting their access to information and ability to support the patient. In some

\* Corresponding author.

E-mail address: [phyllis.butow@sydney.edu.au](mailto:phyllis.butow@sydney.edu.au) (P. Butow).

jurisdictions treatments were delayed, and both patients and families worried about consequential impacts on cancer outcomes [5]. Cancer health professionals (HPs) faced a rapid need to make decisions regarding the most appropriate care for their patients in the context of COVID-19. The possibility that the health system could rapidly become overwhelmed with sick and dying COVID-19 patients was a looming concern. Social distancing rules and the risks and uncertainties surrounding COVID-19 impacted HPs alongside the general community [6]. Thus both the recipients and the providers of cancer care were impacted by COVID-19.

Cancer already carries a high emotional toll; 21% of cancer patients report clinical levels of anxiety or depressive symptoms [7]. Additional fears and uncertainties related to COVID-19, and reduced support from Oncology HPs, family and friends due to stay-at-home orders, can make the cancer experience even more difficult. [8] Similarly, stress and burnout in overworked oncology health professionals who frequently have to deliver bad news is already high, [9] and likely to be exacerbated by the added pressures of COVID-19 [10].

Over 2020 and 2021, reports emerged on the impact of COVID-19 on cancer patients and HPs [8,10–12]. Very few focused on carers. Most studies emerged from Europe, the US and Asia where COVID-19 outbreaks were severe, involving many thousands of deaths and many more cases. In Australia, while there were early restrictions due to COVID-19, cases were contained and effectively suppressed for many months. More recently, there have been COVID-19 (Delta and Omicron variants) outbreaks in Australian cities that have proven harder to contain, requiring extended lockdowns. Nevertheless, the impact (in terms of total case numbers and mortality) has been less severe than in many other parts of the world. Thus, the initial phase of the COVID-19 pandemic in Australia provides an interesting case study of the impact of COVID-19 when the threat of a serious outcome has not yet been fully realised.

The aim of this qualitative study was to document the impact of COVID-19 on the experience of Australians living with cancer, family carers, and Oncology HPs in the acute phase when COVID-19 emerged. As this is a new area of enquiry the study was exploratory and specific hypotheses were not posed.

## 2. Methods

This was a qualitative study with data collected via semi-structured interviews from June to December, 2020 (the first wave of COVID-19 in Australia after the hospital procedures described above had been put into place). Participants also completed measures of emotional morbidity.

### 2.1. Participants

Eligible participants were: a) adult cancer patients (18 years or over) currently receiving or within 6 months of treatment; b) family carers of an eligible cancer patient; and c) oncology HPs (including surgeons, oncology and palliative care doctors and nurses, allied health workers, chaplains and psycho-oncology staff). For patients and carers, non-English speaking or incapacity to give informed consent were exclusion criteria.

### 2.2. Recruitment and study procedure

Participants were recruited through an email invitation via national professional or consumer organisations to maximise regional diversity and cancer type (see Supplementary file 1), two hospital-based oncology services and snowballing (whereby HP participants recommended the study to colleagues by forwarding the introductory email). A participant information sheet, consent form and brief survey was accessible via a link embedded in the email, with

consent provided by ticking a box online. The research team contacted interested participants to schedule a telephone interview. Diversity in age, gender and residence (urban or regional/rural) was ensured where possible.

Recruitment continued until theoretical saturation (i.e., no new emerging themes) was reached within each stakeholder group. The University of Sydney Human Research Ethics Committee and Sydney Local Health District Human Research Ethics Committee granted approval for the study (numbers 2020/351 and 2020/ETH01184 respectively).

### 2.3. Data collection

**Qualitative:** Semi-structured telephone interviews (30–45 min in length) were conducted by experienced qualitative researchers, exploring experiences and impact of COVID-19 on receipt (patients/carers) or delivery (HPs) of cancer services, treatment decision-making, psychosocial outcomes, unmet needs and recommendations regarding optimal support.

**Quantitative:** Demographic, clinical and employment characteristics were elicited at baseline. Psychological wellbeing was assessed using the 14-item, 2-subscale Hospital Anxiety and Depression Scale (HADS) [13] for patients and the 21-item, 3-subscale Depression, Anxiety and Stress Scale (DASS-21) [14] for HPs/carers. Higher subscale scores indicate higher morbidity. Cut-off scores of 0–7 (normal), 8–10 (borderline abnormal) and 11–21 (abnormal) for HADS.

and 0–14 (normal), 19–25 (moderate), 26–33 (severe) and 34 + (extremely severe) for the DASS-21 were used, as recommended in their respective manuals, to categorise responses into severity groups. Both scales have demonstrated reliability and validity in oncology settings [15,16].

### 2.4. Planned analyses

Interviews were audio-recorded, transcribed verbatim, anonymized, uploaded to NVIVO 12 (a computer software package designed to help researchers organise, analyse and find insights in qualitative data), and subjected to thematic analysis using a framework analysis approach [15]. Line-by-line coding was conducted on three transcripts by the research team to develop the preliminary coding framework, which was iteratively refined following review of subsequent transcripts. Over-arching themes and sub-themes were developed to summarise the data. Differences in researcher interpretation of the data were resolved through discussion. Themes arising from participants with higher versus lower anxiety/depression/ stress on the quantitative measures were compared with those scoring lower on those measures. Similar comparisons were made between participant groups. We used the consolidated criteria for reporting qualitative research (COREQ) to guide reporting [16].

Quantitative data analysis was conducted using IBM SPSS Statistics Version 28. Demographic descriptive statistics were generated for all participant groups. Mean subscale scores were calculated for the HADS and DASS-21.

## 3. Results

Demographic and clinical details of participants are presented in Table 1. Thirty-two patients (mean age of 61, 23 female), participated. The majority were diagnosed with breast ( $n = 12$ ; 37%) or prostate ( $n = 9$ ; 28%) cancer. Fifteen participants (47%) had localised disease and 19 (59%) were currently receiving treatment.

Sixteen carers (mean age of 57, 15 female) participated. The majority ( $n = 12$ ; 75%) were a spouse/partner, two were children of a cancer patient, one a parent and one did not respond to this question. Thirteen (81%) lived with the patient.

**Table 1**  
**Cohort characteristics.**

	<b>Patients (N = 32)</b>	<b>Carers (N = 16)</b>	<b>Health professionals (N = 29)</b>
<b>Variable</b>	<b>N (%)<sup>new-a</sup></b>	<b>N (%)</b>	<b>N (%)<sup>new-a</sup></b>
Gender			
Male	9 (28)	1 (6)	2 (7)
Female	23 (72)	15 (94)	27 (93)
Age in years	Mean= 61	Mean= 57	Mean= 48
< 40	4 (13)	2 (13)	9 (31)
41–50	2 (6)	2 (13)	6 (21)
51–60	6 (19)	4 (25)	8 (27)
61–70	14 (44)	7 (44)	4 (14)
71–80	6 (19)	1 (6)	1 (3)
Born in Australia	21 (66)	12 (75)	25 (86)
English spoken at home	32 (100)	14 (88)	27 (93)
Level of Education			
School	5 (16)	1 (6)	0
Technical certificate	8 (25)	2 (13)	1 (3)
Undergraduate degree	9 (28)	4 (25)	4 (14)
Postgraduate degree	10 (31)	9 (56)	24 (83)
Employment			
Employed	9 (29)	7 (44)	28 (96)
Retired	19 (59)	6 (38)	0
Unable to work	2 (6)	6	0
Unemployed	2 (6)	2 (13)	0
Student	0	1 (6)	1 (3)
Time since diagnosis			
< 1 year	12 (38)		
1–5 years	17 (53)		
> 5 years	3 (9)		
Cancer Type			
Breast	12 (38)		
Prostate	9 (28)		
Lung	3 (9)		
Other	8 (25)		
Cancer Stage			
Local	15 (47)		
Locally advanced	5 (16)		
Metastatic	9 (28)		
Other	3 (9)		
Currently on treatment	19 (59)		
Relationship with patient			
Child		2 (13)	
Spouse/ partner		12 (75)	
Parent		1 (6)	
Lives with patient		13 (81)	
Has own medical condition		7 (44)	
Profession			
Oncologist/ palliative care			8 (28)
Nurse			10 (34)
Psycho-oncology			9 (30)
Allied health			2 (7)
Public or private practice			
Public			18 (62)
Private			3 (10)
Mixed			7 (24)

<sup>a</sup> Numbers vary due to a small amount of missing data

Twenty-nine HPs (mean age of 48, 27 female) participated. They included 10 (34%) nurses, 6 (21%) medical oncologists, 9 psycho-oncology staff (30%), 1 palliative care physician, and 2 allied health practitioners (a physiotherapist and genetic counsellor).

### 3.1. Qualitative

Qualitative analysis yielded three shared themes related to the emotional impact of COVID-19: fear and death anxiety, isolation and

uncertainty, with the last theme incorporating a sub-theme unique to HPs: the potential for moral distress and work-stress. Below these themes are explored, with characteristic quotes identified by participant group: (patient (P), carer (C), or HP (HP) and participant ID. For additional quotes, see Table 2.

#### 3.1.1. Fear and death anxiety

Many patients discussed feeling at heightened risk of testing positive for COVID-19 due to being immunocompromised and having to attend hospital for their cancer treatment, where they could not exercise their own precautions. They used emotive language to describe their concern, such as *anxiety*, *worry*, *feeling overwhelmed*, *hypersensitivity*, *hypervigilance*, *desperation*, and *frustration*. Patients and carers feared infecting loved ones or other immune compromised patients in hospital and adopted stringent protective behaviours.

"Would I be as hyper vigilant... if he hadn't had these cancers? Probably not... Because, for me to infect him would be absolutely devastating for me." (C400).

HPs worried that cancer patients might keep away from hospital to avoid the COVID-19 risk.

"...[patients] not actually knowing what the best thing to do – do I go in and keep going with my treatment and risk getting the virus or do I stay at home and not get the virus but don't actually have the cancer treatment." (HP110).

Some patients experienced heightened death anxiety, when thinking about the combined risks of COVID-19 and cancer. One patient said if she got COVID-19 on top of her lung cancer "it's... a hundred percent guaranteed that I would die" (P321). Another patient shared that her lung cancer support group had raised concerns that their medical files would be automatically switched to a "do not resuscitate" status because of risk of COVID-19 spread.

"All these people have been working on me for like four years to try and keep the cancer away and what are we going to do, die of Covid!" (P321).

"The sense of mortality is much stronger than it was... I think the combination of the cancer diagnosis again and the Covid has done that." (P357).

Some carers felt another serious disease on top of cancer would prove too much for the patient's already fragile constitution and psyche. Other carers felt they were trapped in a risky world, which had begun with cancer and now extended to their whole life.

"In my world, I'm still not hugging people, kissing people, touching people... It feels like the whole world to me. It's like you're back living on chemo regime" (C402).

A small proportion of patients and carers felt less at risk of, and worried about, COVID-19 because they perceived a low likelihood of being hit with two bad diagnoses, or felt relatively fit and at no more risk than the general community.

"I've got more to worry about than COVID-19. I couldn't be unlucky enough to have lung cancer at 47 and then get COVID-19." (P318).

HPs described their own sense of heightened risk, and fear of impacting colleagues and patients. Most were concerned that because they worked in hospitals where there was a high chance of contracting COVID-19, they could infect their families, particularly elderly family members, as well as the community.

"...and I worry for myself and my colleagues and our families because, you know, a significant proportion of people who get covid are HPs." (HP102).

#### 3.1.2. Isolation

All participants discussed the impact of isolation due to COVID-19. Several patients noted the challenges of being in hospital without support from family or volunteers. Several noted they were less able to share worries about cancer with others or distract themselves

**Table 2**  
Additional quotes per theme.

Theme 1: Fear and death anxiety	Theme 2: Isolation	Theme 3: Uncertainty
<p>"When I went up for a treatment.... one of the nurses... said, "oh, we've only got one case here." And it just freaked me out... One's enough!" (P326)</p> <p>"So, what built up, was this fear inside of me that I have it and ... suddenly find I'd infected a thousand people and some of them have died" (C406)</p> <p>"I was just really aware that I didn't want to be the one that was responsible for that chain of events, because ...I would feel terribly guilty that all those patients who are currently on chemotherapy couldn't have their chemotherapy at a given time or those ones on radiotherapy had to be all shipped to somewhere else." (HP145)</p>	<p>"There's also been limits on visitors... navigating bags and trying to go the bathroom while I'm attached to the chemo pump... that was really hard to do alone." (328)</p> <p>"It's more depressing if you've got advanced cancer. You've been told you're going to die in a few months, and all you can do is sit at home locked in your house... So, I've probably referred more people to psychology, and I probably started more antidepressants." (HP148)</p> <p>"She had to leave me at the [hospital] doorway... we couldn't even have a hug. That was the single hardest thing in this whole damn process. And I know she said when she went back to the car, she had a good cry." (P343)</p> <p>"It's that thing you don't want to come home and talk about it ... But then... you do feel isolated a little at home because you feel like you can't really have those... conversations." (HP144)</p>	<p>"When I asked..., the risk that that my surgeon and my oncologist both signalled was that I would have my treatment delayed." (P328)</p>

with external activities (such as travel and coffee meetings), leading to adverse psychological impacts. One patient reflected on all the acquaintances in her life who did not know about her diagnosis because she had not seen them and had thus not informed them.

"I think that isolation isn't healthy for me, and it definitely made me anxious." (P325).

"...my way to feel good and feel normal... is to see my friends and do the things that I enjoy doing with them... I don't have that coping mechanism anymore." (P325).

One carer and several HPs noted that isolation from family was especially poignant for some patients who had limited time. HPs also noted some patients transitioning into survivorship felt unable to reengage with life due to lockdown. HPs also noted that patients whose friends and family were overseas and could not travel to Australia were particularly impacted.

"I think that's him saying, if I've only got a shortened life, I don't want to have to give up so much. ... I want to see the kids, cuddle the grandkids. I want them to remember me, not someone 10 feet away." (C401).

"People at the end of their treatment... felt they had just started to regain some independence and some control... And then COVID happened, which meant they couldn't, say, re-join a gym or catch up with friends and family for dinners out." (HP112).

Several patients noted their unmet need for support to overcome these challenges.

"I think for everybody dealing with cancer and a pandemic at the same time, it takes a huge mental toll... it would be nice if there was proactive mental health support" (P323).

In contrast, some patients felt solidarity with other members of the community who also needed to isolate, so they were sharing "*a new normal*" (P318). Another noted the lockdown corresponded with her acute recovery from cancer treatment when she needed to be isolated anyway, thus it was almost "*serendipitous*" (P343). Several patients felt they had more support, because family carers were working from home and were thus more available.

"I wasn't looking at everybody else's life and thinking "oh they are travelling and they're getting on with things because nobody was." (P333).

"And this is probably a terrible thing to say... But just watching everyone else... now they've all had COVID happen to them, and ... I'm thinking, "oh well, now you know how I feel." (P318).

Several HPs also noted these positive impacts.

"Some of my clients have described it as, they've been living these types of restrictions and isolation for a long time and now the

rest of the world has to join them, and they actually feel relieved." (HP104).

Carers discussed feeling excluded and isolated from patient care; patients also noted with sadness, frustration amongst family and friends because they were unable to help. HPs noted that carers with family members with cancer overseas were particularly impacted.

"I'm worried that I just can't be there if she needs me... I want to be there for her." (C408).

"If I'm in the consultation and I hear exactly what he's hearing, I can know whether or not he's downplaying something or whether it's accurate.... But because I'm having to get everything second-hand through him... I feel like I'm out of the loop" (C413).

Carers also discussed feeling isolated from family and friends who would normally offer them support during a difficult time. They found online contact a poor substitute for face-to-face contact. In-person catch ups, when they occurred, were often awkward with masks and social distancing. One carer described the pain of having to refuse access to her daughter's funeral.

"Everything fell on me. Because I live under the same roof as my mum, we couldn't have visitors so none of my siblings could help." (C800).

"People wanting to come and visit her... And then having to do the same thing at the funeral... you can't come." (C409).

HPs also noted that carers had less support from the treating team due to COVID-19.

"Their anxiety levels are often much higher than the person who has cancer... because they don't have the care team ..., interacting with them all the time [as usual]." (HP127).

HPs reflected on their own isolation, on their distress at being unable to seek or give comfort to family and friends outside the home. Some felt they could not burden family and friends with COVID-19-related challenges they were witnessing at work. They missed interaction with colleagues because they were working from home or having to socially distance in the workplace. In contrast a couple of HPs appreciated having less pressure to socialise, and felt energised by overcoming the daily challenges of COVID-19.

"it's lack of social contact with friends and family. So, it was all really difficult." (HP106).

"... to be honest, I'm an introvert... so I was fine not having to socialise every weekend, I was like that's fine." (HP105).

To combat isolation, HPs discussed participating in regular online team meetings to debrief. Most HPs felt supported by their employers who offered access to mental health assistance, employee



assistance programs, virtual team building exercises and manager support. Several HPs mentioned the support of family and friends.

"I've been trying to do the team meetings more regularly than usual... you don't feel alone in the running of things. the only one that is navigating it... ..then it's for checking in, of how are you going? Are you ok?" (HP104).

"Just with the support of my colleagues and my friends and family... we're all in it together." (HP101).

#### 4. Uncertainty

Patients' uncertainty about their cancer diagnosis and its implications was intensified by the extra layer of uncertainty COVID-19 invoked, and reduced face-to-face contact with the Oncology team. Like cancer, COVID-19 was seen as an invisible enemy. While most patients and carers believed their treatment had not changed as a result of COVID-19, they worried about future treatment impacts and lengthy lockdowns, and unknowns regarding how COVID-19 and cancer intersect. One patient was unsure whether she would be eligible for vaccination when available.

"Covid brings in another danger where it's partly because you can't see it..." (P357).

"I think one thing that Covid did was it bought back that whole feeling of when the blocks get knocked out from under you when you get a cancer diagnosis" (C402).

"I think there was just a little bit more uncertainty [from] not being able to ask as many questions because she wasn't in the same room as her clinicians." (C408).

Uncertainty was closely related to the heightened sense of risk and death anxiety discussed in theme 1.

"This thing happens, it's totally out of the blue..., turns your life upside down, and you get really scared. You don't know what's happening, and the uncertainty is a big part of that, and fear of your health and fear of death." (HP105).

HPs noted they now had a shared experience with their cancer patients of living with uncertainty, and that cancer patients "actually have some very wise words to share about living in that kind of limbo." (HP128).

##### 4.1. The potential for moral distress and work-stress

Uncertainty for HPs uniquely also focused on treatment decisions they may have to make on behalf of their patients should the COVID outbreak worsen in Australia (and the moral distress that would invoke), how they would cope if their workforce was overburdened by colleagues becoming ill or having to self-isolate, and whether reductions in screening would result in a tidal wave of late-presenting cancers.

"... initially it was most concerning when we're really uncertain what was going to happen..." (HP507).

"We expected that we'd have a lot of HPs going down so that we would be in a situation of not only being overwhelmed with patients but being overwhelmed with not having enough HPs to look after them and lots of people being redeployed." (HP101).

"There were a lot of nurses who were very distressed ... about who they were going to have to turn away." (HP101).

HPs coped with uncertainty by being prepared and following their own advice given to patients.

"I just put some of the strategies that you recommend to your clients to do really... self-care and reach out to others if you needed a little bit of extra support." (HP145).

There were no other clear distinctions between participant groups.

#### 4.2. Quantitative

On HADS, anxiety and depression levels were relatively low, with median levels all within the normal range. Four (12%) and 9 (28%) patients reported scores probably or possibly indicating anxiety or depression (see [Supplementary Table 2](#)). On DASS, three carers (19%) scored in the higher ranges for anxiety/depression. Two HPs (7%) scored in the severe and 7 (24%) in the moderate range for anxiety/depression/stress.

At interview, participants scoring high on anxiety/depression/stress measures expressed more intense anxiety related to COVID-19, talked about taking more extreme precautionary measures, and felt more impacted by isolation, than those scoring low. One patient scoring high on depression talked about being under a constant "black cloud" of fear (P321). Patients and carers scoring high were more likely to have metastatic or locally advanced cancers, and expressed greater death anxiety, feeling that COVID-19 would almost certainly prove deadly if added to their existing poor cancer prognosis. The few HPs scoring high on quantitative measures discussed feeling stressed, burned out and in need of a holiday, isolated, and were conscious of mental health issues in the community and their patients.

#### 5. Discussion and conclusions

##### 5.1. Discussion

This is one of the first studies to examine experiences of the COVID-19 pandemic of multiple stakeholders involved in receiving or providing cancer care, and highlights that all cancer stakeholders, including HPs, are impacted, even in the relatively mild COVID-19 context of Australia. All stakeholders faced the intertwined issues of fear and death anxiety, isolation and uncertainty in confronting a life-threatening disease. This shared experience appeared to heighten awareness and understanding of others' emotions. Each of our participant groups expressed concern for others; patients worried about carers' isolation and frustration, carers were hypervigilant in protecting the patient and HPs were very aware of the psychological challenges faced by their patients and carers. In some instances, this shared experience appeared to create comfort, with some patients describing a sense of reduced isolation stemming from shared vulnerability with the general population.

A strong theme that emerged from the data, was the compounding impact of cancer and COVID-19 on fear and death anxiety, arising from perceptions of increased physical vulnerability and compounding psychological responses. Death anxiety is a feeling of panic, fear or worry caused by thinking of death, being detached from the world, or what will happen after life [17]. There is an emerging literature [17–19] suggesting that COVID-19-related death anxiety is a significant contributor to increasing levels of anxiety and depression reported worldwide. Sharpe et al. [20] noted that death anxiety is a prominent theme in community and patient discourse about cancer and cancer recurrence. Our patient/carer participants, particularly those with metastatic cancer, reported that their existential anxieties, already heightened by cancer, now seemed to extend to the whole world. Those who expressed these fears most cogently also scored higher on the anxiety and depression measures. Thus cancer, still so strongly associated with death in many people's minds [21] despite significant treatment advances, may compound COVID-19 related fears and leave this population particularly vulnerable to depression and anxiety.

Despite death anxiety being understood to be part of the human condition, an 'existential given,' [22] meta-analytic findings suggest that psychosocial intervention, notably cognitive-behavioural therapy, can reduce death anxiety [23]. The importance of addressing mental health during the pandemic has been strongly

emphasised, [24] but the compounding impacts on those with chronic conditions, including cancer, suggests a need for a particular mental health focus on these more vulnerable populations.

Another dominant theme raised by all participant groups was isolation, as has also been widely noted in the general population [25]. HPs who were under increased work stress noted the lack of face-to-face support from colleagues and friends. For patients, isolation was felt at all phases of their cancer journey. For those at the end of life, the inability to be with loved ones was particularly poignant. This theme of isolation has been acknowledged in a number of surveys of cancer patients internationally [26,27]. Calls for greater compassionate access and increased provision of creative alternatives to face-to-face support (for example, through psycho-oncology online services, compassionate communities and social media) have been made [28–30].

Participants in this study noted significant uncertainty in relation to COVID-19 and its potential impacts on current and future cancer treatment, compounding existing cancer-related uncertainties [31,32]. HPs described a sense of kinship with their patients over these shared uncertainties. Uncertainty interventions, such as those developed for patients struggling with fear of cancer recurrence, [33] may be helpful for many in the cancer community at this time.

For HPs only, uncertainty also centred around fears of a worsening situation in which overwhelmed health staff would be forced to make decisions invoking moral distress, a theme noted in other COVID-19 studies [34]. Hlubocky et al. [35] called healthcare organisations to account, enjoining them to support oncologists by protecting staff, providing truthful, transparent COVID-19 care information and preventing coercive situations that could cause moral distress. Along with higher rates of reported depression and anxiety in cancer patient samples (37% and 38% respectively reported in a recent meta-analysis of self-reported outcomes in cancer patients during COVID-19) [36] these results suggest that screening for distress in cancer patients, and for stress and burnout in oncology HPs, with linked interventions for those in need, is called for. Such screening is already widely endorsed for cancer patients [37] and HPs, [38] with validated brief scales (such as the distress thermometer [39] for patients and a recently developed stress and burnout measure specific to pandemic scenarios for health professionals [40]) readily available. With the potential for the Oncology workforce to be overwhelmed or redeployed into COVID-19 care, [41] innovative methods will be needed. Web-based symptom screening methods, which overcome the barriers of remote care and fewer clinic-based follow-ups, have been shown to be acceptable and feasible, albeit with variable uptake, [42] and may be a useful model to consider during pandemics.

This study had some limitations. The sample size was driven by the qualitative methodology, thus further studies are required to assess the generalisability of our findings. Our sample showed some selection bias with over-representation of women, and those with breast cancer, a common problem in psychosocial research. The COVID-19 pandemic has continued to evolve, with new variants bringing changed conditions, vaccines providing hope and more discoveries increasing our knowledge base from month to month. However, the study also had strengths. By including all cancer stakeholders, we were able to document shared perspectives and experiences across groups. The mixed methods data enabled comparison of objective anxiety and depression data with subjective experience. Future analyses should explore longitudinal experiences, tracking changing well-being as the pandemic progresses.

## 5.2. Conclusions

In this study of oncology patients, family members and HPs, all groups experienced fear and death anxiety, isolation and uncertainty

associated with living with and treating cancer during the COVID-19 pandemic, and were aware of this shared experience.

## 5.3. Practice Implications

To address these significant added pressures, screening for distress in patients, and burnout in HPs, is recommended. Increased compassionate access and provision of creative alternatives to face-to-face support are warranted for patients and their families, as well as systemic support for HPs.

## CRedit authorship contribution statement

**Butow P:** Conceptualisation, Methodology, Writing – original and draft, Writing – review & editing. **Havard PE:** Methodology, Formal analysis, Investigation, Data Curation, Writing – original and draft, Writing – review & editing. **Butt Z:** Methodology, Investigation, Data curation. **Juraskova I:** Methodology, Writing – review & editing. **Sharpe L:** Methodology, Writing – review & editing. **Dhillon H:** Methodology, Writing – review & editing. **Beatty L:** Methodology, Writing – review & editing. **Beale P:** Methodology, Writing – review & editing. **Cigolini M:** Methodology, Writing – review & editing. **Kelly B:** Methodology, Writing – review & editing. **Chan RJ:** Methodology, Writing – review & editing. **Kirsten L:** Methodology, Writing – review & editing. **Best M:** Methodology, Writing – review & editing. **Shaw J:** Conceptualisation, Methodology, Supervision, Project administration, Writing – original & draft, Writing – review & editing.

## Declarations of interest

none.

## Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2022.01.020](https://doi.org/10.1016/j.pec.2022.01.020).

## References

- [1] Li SH, Beames JR, Newby JM, Maston K, Christensen H, Werner-Seidler A. The impact of COVID-19 on the lives and mental health of Australian adolescences. *Eur Child Adolesc Psychiatry* 2021;28:1–13. <https://doi.org/10.1007/s00787-021-01790-x>
- [2] Knolle F, Ronan L, Murray GK. The impact of the COVID-19 pandemic on mental health in the general population: a comparison between Germany and the UK. *BMC Psychol* 2021;9:60. <https://doi.org/10.1186/s40359-021-00565-y>
- [3] World Health Organization. Mental health and psychosocial considerations during the COVID-19 outbreak. 2020; Available from: <https://www.who.int/docs/default-source/coronavirus/mental-health-considerations.pdf>.
- [4] Carreira H, Strongman H, Peppia M, McDonald HI, Dos-Santos-Silva I, Stanway S, et al. Prevalence of COVID-19-related risk factors and risk of severe influenza outcomes in cancer survivors: a matched cohort study using linked English electronic health records data. *Lancet* 2020;29:100656. [doi.org/10.1016/j.eclinm.2020.100656](https://doi.org/10.1016/j.eclinm.2020.100656).
- [5] Chia JMX, Goh ZS, Chua ZY, et al. Managing cancer in context of pandemic: a qualitative study to explore the emotional and behavioural responses of patients with cancer and their caregivers to COVID-19. *BMJ Open* 2021;11:e041070. [10.1136/bmjopen-2020-041070](https://doi.org/10.1136/bmjopen-2020-041070).
- [6] Hlubocky FJ, Back AL, Shanafelt TD, Gallagher CM, Burke JM, Kamal AH, et al. Occupational and personal consequences of the COVID-19 pandemic on US oncologist burnout and well-being: a study from the ASCO clinical well-being task force. *JCO Oncol Pr* 2021;17:427–37.
- [7] Mitchell AJ, Chan M, Bhatti H, Halton M, Grassi L, Johansen C, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011;12(2):160–74.
- [8] Edge R, Mazariego C, Li Z, et al. Psychosocial impact of COVID-19 on cancer patients, survivors, and carers in Australia: a real-time assessment of cancer support services. *Support Care Cancer* 2021;29(9):5463–73. <https://doi.org/10.1007/s00520-021-06101-3>
- [9] Yates M, Samuel V. Burnout in oncologists and associated factors: a systematic literature review and meta-analysis. *Eur J Cancer Care* 2019;28:e13094.

- [10] Drury A, Eicher M, Dowling M. Experiences of cancer care during COVID-19: phase 1 results of a longitudinal qualitative study. *Int J Nurs Stud Adv* 2021;3:100030.
- [11] Hyland KA, Jim HSL. Behavioral and psychosocial responses of people receiving treatment for advanced lung cancer during the COVID-19 pandemic: a qualitative analysis. *Psychooncology* 2020;29(9):1387–92. <https://doi.org/10.1002/pon.5445>
- [12] Wiener L, Fry A, Pelletier W, Cincotta N, Jones B. The impact of COVID-19 on the professional and personal lives of pediatric oncology social workers. *J Psychosoc Oncol* 2021;39(3):428–44. <https://doi.org/10.1080/07347332.2021.1912245>
- [13] Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67(6):361–70.
- [14] Lovibond SH, Lovibond PF. Manual for the Depression Anxiety Stress Scales. Second ed., Sydney: Psychology Foundation; 1995.
- [15] Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:1–8.
- [16] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care* 2007;19:349–57.
- [17] Khademi F, Moayedi S, Golitaleb M, Karbalaie N. The COVID-19 pandemic and death anxiety in the elderly. *Int J Ment Health Nurs* 2020. <https://doi.org/10.1111/inm.12824>
- [18] Menzies RE, Menzies RG. Death anxiety in the time of COVID-19: theoretical explanations and clinical implications. *Cogn-Behav Ther* 2020;13:e19. <https://doi.org/10.1017/S1754470x20000215>
- [19] Pérez-Mengual N, Aragonés-Barbera I, Moret-Tatay C, Moliner-Albero AR. The Relationship of fear of death between neuroticism and anxiety during the COVID-19 pandemic. *Front Psychiatry* 2021;12:501. <https://doi.org/10.3389/fpsy.2021.648498>
- [20] Sharpe L, Curran L, Butow P, Thewes B. Fear of cancer recurrence and death anxiety. *Psycho Oncol* 2013;27:2559–65.
- [21] Moser RP, Arndt J, Jimenez T, Liu B, Hesse BW. Perceptions of cancer as a death sentence: tracking trends in public perceptions from 2008–2017. *Psycho Oncol* 2021;30(4):511–9.
- [22] Yalom ID. Existential Psychotherapy. New York, USA: Basic Books; 1980.
- [23] Menzies RE, Zuccala M, Sharpe L, Dar-Nimrod I. The effects of psychosocial interventions on death anxiety: a meta-analysis and systematic review of randomised controlled trials. *J Anxiety Disord* 2018;59:64–73. <https://doi.org/10.1016/j.janxdis.2018.09.004>
- [24] Li W, Yang Y, Liu ZH, et al. Progression of mental health services during the COVID-19 outbreak in China. *Int J Biol Sci* 2020;16(10):1732.
- [25] Smith BJ, Lim MH. How the COVID-19 pandemic is focusing attention on loneliness and social isolation. *Public Health Res Pr* 2020;30(2):e3022008.
- [26] Davis C, Cadet T, Rune K, Wilson P, Banks J. Exploring the challenges in accessing care and support for cancer survivors in Australia during COVID-19. *J Psychosoc Oncol* 2021;39(3):479–84. <https://doi.org/10.1080/07347332.2021.1904086>
- [27] Hulbert-Williams NJ, Leslie M, Hulbert-Williams L, Smith E, Howells L, Pinato DJ. Evaluating the impact of COVID-19 on supportive care needs, psychological distress and quality of life in UK cancer survivors and their support network. *Eur J Cancer Care* 2021:e13442. <https://doi.org/10.1111/ecc.13442>
- [28] Millar C, Cambell S, Fisher P, Hutton J, Morgan A, Cherry MG. Cancer and COVID-19: patients' and psychologists' reflections regarding psycho-oncology service changes. *Psycho Oncol* 2020;29:1402–3.
- [29] Wakam GK, Montgomery JR, Biesterveld BE, Brown CS. Not dying alone – modern compassionate care in the COVID-19 pandemic. *New Engl J Med* 2020;382:e88. <https://doi.org/10.1056/NEJMp2007781>
- [30] Abel J, Taubert M. Coronavirus pandemic: compassionate communities and information technology. *BMJ Support Palliat Care* 2020;10:369–71.
- [31] Etkind SN, Bristowe K, Bailey K, Selman LE, Murtagh FE. How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data. *Palliat Med* 2017;31(2):171–80.
- [32] Maheu C, Singh M, Tock WL, Eyrenci A, Galica J, Hebert M, et al. Fear of cancer recurrence, health anxiety, worry and uncertainty: a scoping review about their conceptualization and measurement within breast cancer survivorship research. *Front Psychol* 2021. <https://doi.org/10.3389/fpsyg.2021.644932>
- [33] Guan T, Qan'ir Y, Song L. Systematic review of illness uncertainty management interventions for cancer patients and their family caregivers. *Support Care Cancer* 2021;29(8):4623–40. <https://doi.org/10.1007/s00520-020-05931-x>
- [34] Rashid S, Reeder C, Sahu S, Rashid S. Psychological distress and moral injury to oncologists and their patients during COVID-19 pandemic. *Curr Psychol* 2021;1–6. <https://doi.org/10.1007/s12144-021-02128-1>
- [35] Hlubocky FJ, Symington BE, McFarland DC, Gallagher CM, Dragnev KH, Burke JM, et al. Impact of the COVID-19 pandemic on oncologist burnout, emotional well-being, and moral distress: Considerations for the cancer organization's response for readiness, mitigation, and resilience. *JCO Oncol Pract* 2021;17(7):365–75.
- [36] Ayubi E, Bashirian S, Khazaei S. Depression and anxiety among patients with cancer during COVID-19 pandemic: a systematic review and meta-analysis. *J Gastrointest Cancer* 2021;52(2):499–507. <https://doi.org/10.1007/s12029-021-00643-9>
- [37] Butow P, Price MA, Shaw JM, Turner J, Clayton JM, Grimison P, et al. Clinical pathway for the screening, assessment and management of anxiety and depression in adult cancer patients: Australian guidelines. *Psychooncology* 2015;24(9):987–1001. <https://doi.org/10.1002/pon.3920>
- [38] Hansen V, Giris A. Can a single question effectively screen for burnout in Australian cancer care workers? *BMC Health Serv Res* 2010;10:341. <https://doi.org/10.1186/1472-6963-10-341>
- [39] Mitchell AJ. Pooled results from 38 analyses of the accuracy of the distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *J Clin Oncol* 2007;25:4670–81.
- [40] Prasad K, McLoughlin C, Stillman M, Poplau S, Goelz E, Taylor S, et al. Prevalence and correlates of stress and burnout among U.S. healthcare workers during the COVID-19 pandemic: a national cross-sectional survey study. *EclinicalMedicine* 2021;35:100879. <https://doi.org/10.1016/j.eclim.2021.100879>
- [41] Chan A, Ashbury F, Fitch MI, Koczwara B, Chan RJ, MASCC Survivorship Study Group. Cancer survivorship care during COVID-19-perspectives and recommendations from the MASCC survivorship study group. *Support Care Cancer* 2020;28(8):3485–8. <https://doi.org/10.1007/s00520-020-05544-4>
- [42] Cho Y, Zhang H, Harris MR, Gong Y, Smith EL, Jiang Y. Acceptance and use of home-based electronic symptom self-reporting systems in patients with cancer: systematic review. *J Med Internet Res* 2021;23(3):e24638. <https://doi.org/10.2196/24638>